

Portuguese Adaptation and Validation of the Social Activities Checklist

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Introduction and aims

Social participation of people with aphasia (PWA) is a growing concern in healthcare (Dalemans et al., 2010). PWA report as social consequences of aphasia in their daily life a decrease in communicative initiative, reduction of communicative partners and social activities, loss of activities shared with friends, and the need for socialisation (Cruice et al., 2020; Manning et al., 2019). PWA also refer the existence of feelings of sadness, despair, anxiety and loneliness, lack of energy, low interest and motivation to start activities, low self-esteem and the feeling of being trapped, which makes them retract from social contact (Cruice et al., 2020). In Portugal, the number of tools capable of assessing these difficulties is scarce (Matos, 2012; Matos et al., 2014). We have therefore translated to European Portuguese (EP) and validated the Social Activities Checklist (SOCACT) that will allow the assessment of social participation of PWA in Portugal.

Methods

This is a methodological, observational, descriptive-correlational study consisting of different phases: Translation of SOCACT into EP; back-translation; evaluation of the different versions by a committee of experts (N=6); cognitive debriefing with a group of five PWA (content validation). A pilot study was implemented with 15 PWA and 30 neurologically healthy people (NHP). Participants were recruited at the Portuguese Institute of Aphasia (IPA), in Matosinhos, according to the following inclusion criteria: Both sexes; over 18 years of age; EP as their first language; literate; people living at home; having at least 3 months post onset; with no hearing problems that interfered in the communication process; having an aphasia diagnosis according to the Lisbon Aphasia Assessment Battery - BAAL (Caldas, 1979; Damásio, 1973; Ferro, 1986), a reliable yes/no response (no less than 7 on the BAAL yes/no questions, with a total score of 8 points); no presumed cognitive disorder according to the Language Mini Mental State Examination - LMMMSE (Pashek, 2008) EP version (Matos and Jesus, 2011) and also according to the information in the clinical history of the person; no presumed depression according to the Center For Epidemiologic Studies Depression Scale - CES-D (Radloff, 1979) EP version (Gonçalves and Fagulha, 2004); be able to understand simple sentences according to the sub-test of the Language and Aphasia Assessment Tests in Portuguese - PALPA-P (Castro et al., 2007). Content validity was

analysed from a qualitative point of view (individual and group interviews) and quantitatively (Content Validity Index - CVI). The Chi-Square test and the Fisher test were used to compare both groups (categorical variables) and independent samples t-test and Mann-Whitney test were used to compare continuous variables. To assess the internal consistency (IC), Cronbach's α was used. Test-retest results (7 days interval) were analysed using the Wilcoxon test and the Cohen's Kappa test. Spearman's Correlation test was used to analyse the concurrent validity with the Communication Disability Profile's (CDP) participation subscale.

Results

PWA found the SOCACT-EP and its instructions easy to understand and to fill, and with the adequate length. They considered it relevant with clear and unambiguous questions. For most questions, CVI obtained was 1, which shows a great agreement between experts regarding the different characteristics of the Checklist. For PWA, Cronbach's α in the Social Activities section was 0.660 (total), 0.325 (Leisure category), 0.661 (Informal category) and 0.244 (Formal category). For the NHP group, Cronbach's α was 0.773 (total), 0.574 (Leisure category), 0.398 (Informal category) and 0.759 (Formal category). It was not possible to calculate Cronbach's α for the Social Activities Partners section, because the groups of PWA was too small and there were many missing values in both groups. When analysing the differences between groups in the Social Activities section, it is possible to understand that some activities differ greatly among them. PWA reported difficulties arising from aphasia and physical restrictions. The test-retest results revealed that, for the ordinal scale (Social Activities section), there were no major discrepancies regarding the frequencies of activities carried out by PWA in the two periods of application of SOCACT-EP, showing good reliability. For the nominal scale (Social Activities Partners section), it was possible to see that, in more than half of the activities there was no test-retest reliability, as people changed their opinion in both assessments in relation to those with whom they carry out the activity. For the concurrent validity no significant correlations were found between SOCACT-EP and CDP's participation sub-scale.

Discussion

This study aimed to translate SOCACT into EP and analyse its validity and reliability. SOCACT-EP presented a good CVI, and it was considered relevant, easy to understand, easy to fill in, with clear and unambiguous questions, and having an adequate length. Unfortunately, it presented a low IC in the Social Activity section. These results are not surprising as they are in agreement with another published study on the psychometric characteristics and internal consistency of SOCACT (Aujla et al., 2015). According to these authors, the Cronbach's α from the Checklist (total and by category) was very low (Total

0.58; Leisure 0.55; Informal -0.25; Formal 0.24) even though they had a larger sample. They have considered the fact of a relationship between a health condition and social activity participation not always being explicit as a possible explanation for this low IC. In addition, there were also some differences in the activities carried out between both groups (PWA and NHP) and the concurrent validity was also low.

Conclusion

Despite the work done, more research on social participation and on the SOCACT-EP is still needed, as the sample involved in the study was not representative of the Portuguese PWA population. It will be important to use a larger and more diverse sample in order to improve the Checklist. It is also necessary to develop more instruments to assess this domain and thus help PWA to achieve their goals and needs.

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